

## Calendar No. 529

113TH CONGRESS  
2D SESSION**H. R. 594**

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IN THE SENATE OF THE UNITED STATES

JULY 29, 2014

Received

AUGUST 1, 2014

Read twice and placed on the calendar

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**AN ACT**

To amend the Public Health Service Act relating to Federal research on muscular dystrophy, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Paul D. Wellstone  
5 Muscular Dystrophy Community Assistance, Research and  
6 Education Amendments of 2014”.

7 **SEC. 2. INITIATIVE THROUGH THE DIRECTOR OF THE NA-**  
8 **TIONAL INSTITUTES OF HEALTH.**

9 Section 404E of the Public Health Service Act (42  
10 U.S.C. 283g) is amended—

1 (1) in subsection (a)(1)—

2 (A) by striking “Muscoskeletal” and in-  
3 serting “Musculoskeletal”; and

4 (B) by inserting “Becker, congenital mus-  
5 cular dystrophy, limb-girdle muscular dys-  
6 trophy,” after “Duchenne,”;

7 (2) in subsection (b)—

8 (A) in paragraph (2)—

9 (i) by striking “genetics,” at the sec-  
10 ond place it appears; and

11 (ii) by inserting “cardiac and pul-  
12 monary function, and” after “imaging,”;

13 and

14 (B) in paragraph (3), by inserting “and  
15 sharing of data” after “regular communica-  
16 tion”;

17 (3) in subsection (d)—

18 (A) in paragraph (2)—

19 (i) in the matter preceding subpara-  
20 graph (A), by striking “15” and inserting  
21 “18”; and

22 (ii) in subparagraph (A)—

23 (I) by striking “and the Food  
24 and Drug Administration” and insert-  
25 ing “, the Food and Drug Administra-

1                   tion, and the Administration for Com-  
2                   munity Living”;

3                   (II) by inserting “and adults”  
4                   after “children”; and

5                   (III) by striking “such as the De-  
6                   partment of Education” and inserting  
7                   “including the Department of Edu-  
8                   cation and the Social Security Admin-  
9                   istration”; and

10                  (B) in paragraph (4)(B), by inserting “,  
11                  but shall meet no fewer than two times per cal-  
12                  endar year” before the period; and

13                  (4) in subsection (e)—

14                   (A) in paragraph (1)—

15                   (i) in the matter preceding subpara-  
16                   graph (A), by striking “through the na-  
17                   tional research institutes” and inserting  
18                   “through the agencies represented on the  
19                   Coordinating Committee pursuant to sub-  
20                   section (d)(2)(A)”;

21                   (ii) in subparagraph (A)—

22                   (I) by inserting “public services,”  
23                   before “and rehabilitative issues”; and

24                   (II) by inserting “, studies to  
25                   demonstrate the cost-effectiveness of

1 providing independent living resources  
2 and support to patients with various  
3 forms of muscular dystrophy, and  
4 studies to determine optimal clinical  
5 care interventions for adults with var-  
6 ious forms of muscular dystrophy”  
7 after “including studies of the impact  
8 of such diseases in rural and under-  
9 served communities”; and

10 (B) in paragraph (2)(D), by inserting after  
11 “including new biological agents” the following:  
12 “and new clinical interventions to improve the  
13 health of those with muscular dystrophy”.

14 **SEC. 3. SURVEILLANCE AND RESEARCH REGARDING MUS-**  
15 **CULAR DYSTROPHY.**

16 The second sentence of section 317Q(b) of the Public  
17 Health Service Act (42 U.S.C. 247b–18(b)) is amended  
18 by inserting before the period the following: “and, to the  
19 extent possible, ensure that data be representative of all  
20 affected populations and shared in a timely manner”.

21 **SEC. 4. INFORMATION AND EDUCATION.**

22 Section 5(c) of the Muscular Dystrophy Community  
23 Assistance, Research and Education Amendments of 2001  
24 (42 U.S.C. 247b–19(c)) is amended—

25 (1) in paragraph (2)—

1 (A) by inserting “for pediatric and adult  
2 patients, including acute care considerations,”  
3 after “issuance of care considerations”;

4 (B) by inserting “various” before “other  
5 forms of muscular dystrophy”; and

6 (C) by striking “and” at the end;

7 (2) by redesignating paragraph (3) as para-  
8 graph (4);

9 (3) by inserting after paragraph (2) the fol-  
10 lowing:

11 “(3) in developing and updating care consider-  
12 ations under paragraph (2), incorporate strategies  
13 specifically responding to the findings of the national  
14 transitions survey of minority, young adult, and  
15 adult communities of muscular dystrophy patients;  
16 and”; and

17 (4) in paragraph (4), as redesignated, by insert-  
18 ing “various” before “other forms of muscular dys-  
19 trophy”.

Passed the House of Representatives July 28, 2014.

Attest:

KAREN L. HAAS,

*Clerk.*

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